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SEVENTH FRAMEWORK
PROGRAMME

The Diabetes Literacy Project: Strengthening diabetes self-management in Europe

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For the Diabetes Literacy Consortium

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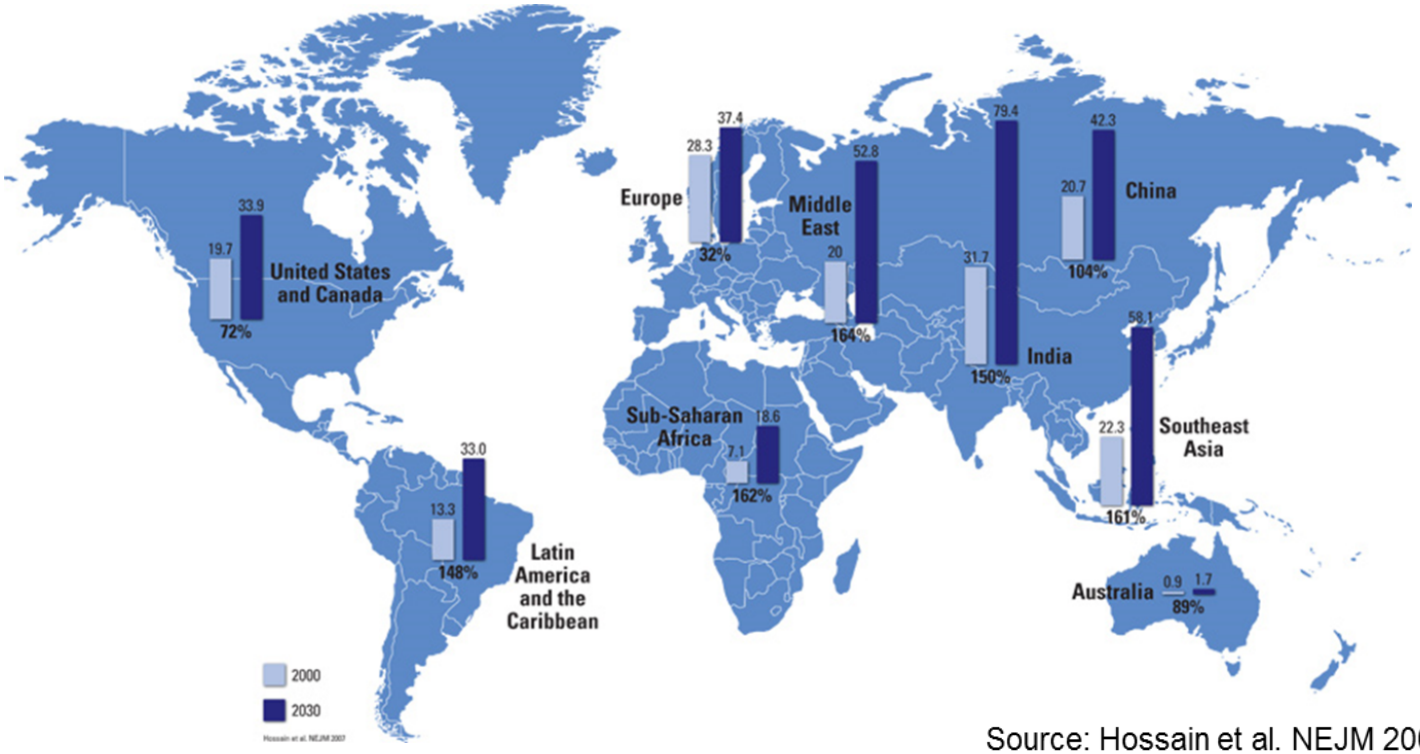
The challenge of diabetes

- 387 million patients worldwide
  - 50% unaware that they have diabetes
- 4th cause of death in the EU
  - 300.000 deaths per year
- 5 to 15% of health care costs

- Impact of growing obesity and an ageing population
  - ➔ Increased number of people with diabetes
  - ➔ Increased health care costs related to diabetes



Source: Hossain et al. NEJM 2007 *(million people)*

The importance of self-management

- A key determinant of treatment outcome, as diabetes requires intensive self-care
- Enhancing self-management requires patient empowerment
- Questions regarding diabetes self-management education (DSME)

- Which DSME programs are available (in the EU) ?
- What is the (cost)- effectiveness of different approaches?
  - ➢ effectiveness of individual-based diabetes education programs has been proven, but not the cost-effectiveness

  - ➢ group education, self-help support or IT supported education may be more (cost-)effective, but comparative studies of DSME approaches are scarce

- What are the conditions for effectiveness ?

  e.g., characteristics of health care system, quality of implementation, …

- What patient characteristics moderate the effectiveness?

  Health literacy of Europeans: 10% inadequate and 35% limited HL

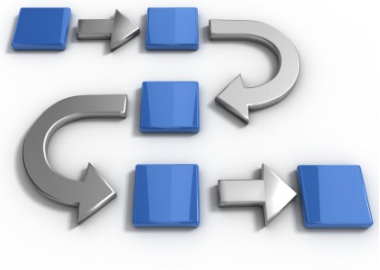
The Diabetes Literacy project

- A European project, funded by the EU through the 7th Framework Programme for Research
- A consortium of organizations from 6 EU Member States (B, D, IRL, NL, A, UK) + Israel, USA and Taiwan

  + DK and South Africa as collaborating partners
- Aims to provide empirical evidence to increase the effectiveness of self-management education for Type 2 diabetes in adults

Aims of the Diabetes Literacy project

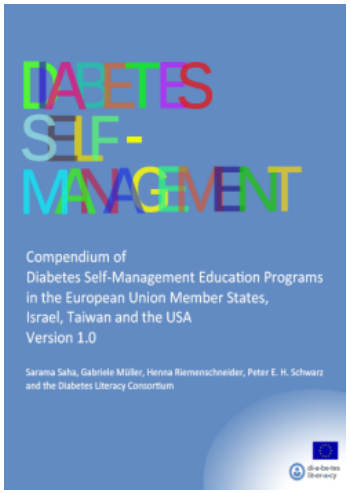
- Perform a content analysis of national diabetes strategies (policies and programs) across the EU
- Assess the (cost-) effectiveness of different formats of diabetes self-management education
- Investigate
  - the mediating role of implementation fidelity on program effectiveness
  - the moderating role of the patients' health literacy and of organizational characteristics (e.g., ease of access, multidisciplinary staff, patient monitoring system)
- Develop and pilot-test low literacy-appropriate ICT-materials for diabetes self-management education



Methodology

- Surveys among stakeholders
  - Description of the nature and quality of the national diabetes strategies via expert interviews
  - Inventory and description of existing DSME programs via Global Diabetes Survey + online wiki tool
  - assessment of existing costing practices against best practice costing models
- Comparative clinical study
  - Compare effectiveness and cost-effectiveness of different types of DSM education programs
  - Investigate potential moderating or mediating factors for effectiveness (organisation, implementation, patient health literacy)
- Development and pilot testing of online educational materials for diabetes patients with low literacy

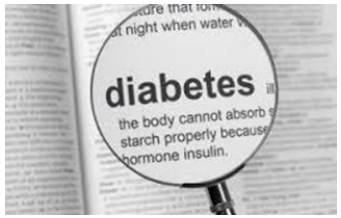
Main Findings



- A wide variety of DSME programs is available in Europe
  - Most programs use **group interventions** to empower patients to manage their diabetes
  - Peer-led support and IT-based programs are less common throughout Europe
  - Existing programs are **not equally distributed** in the population and do not reach all target groups

    40-60% of patients do not take part in diabetes education
  - **Patient participation** in planning and a participatory approach to program implementation are under-utilized

- Costs of diabetes self-management education
  - Costs **vary greatly** between countries and between programs within countries in the EU, as well as Taiwan and Israel
  - Compared to the overall costs of diabetes care and the treatment of complications, the **costs of DSME programs are low** (generally below € 20 per patient/hour)



Main Findings

- Effectiveness of DSME
  - Overall, DSME programs are **effective** in changing behavior and improving problem solving, healthy coping, and health related quality of life
  - There is no systematic significant difference in the effectiveness of different **formats** of programs (individual, group, self-help, IT-based)
  - Most of the intervention outcomes improved after the intervention, **regardless of the provider's adherence** to the program guidelines

    For some outcomes, adapting the way in which the program is delivered (not the content) is associated with a greater improvement

- The potential of online support to self-management
  - A **good design** of web-based programs is more important than adding interactive and audiovisual materials elements
  - It is possible to develop web-based materials that are accessible to those with **lower health literacy** but also liked by those with higher literacy

Health Literacy and DSME

- Two roles of health literacy in DSME
  - An **outcome of DSME**: people who participate in DSME enhance their competence to successfully self-manage their disease
  - A **moderator** of effectiveness: people with low health literacy can be expected to benefit less from DSME

- Health literacy in the Diabetes Literacy study
  - As a patient characteristic (general HL, measured via HLS-EUQ6)
  - As an outcome of DSME (diabetes-specific HL, measured via DHL Scales)
- Findings
  - Significant main effects of HL on outcomes of DSME
  - No differences in effectiveness of DSME between people with high and low health literacy

Conclusions

- There is a window of opportunity in Europe to empower diabetes patients to successful self-manage their disease
- Rather than investing in the development of new DSME programs, **existing programs should be made more available and accessible** to patients, and more tailored to cultural and health literacy needs of the participant
- Intensifying and improving the **training of providers** of self-management education, including a greater focus on behavioural and psychological expertise, is essential to ensure the quality of DSME programs

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